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PRINCIPAL INVESTIGATOR: Dr. Robert R. Redfield

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14. ABSTRACT December 12, 2011 PAN hosted a national webcast How the FDA Impacts the Parkinson's Community featuring leading experts on this issue. This discussion focused on this 90-minute webcast provided important information to help inform the Parkinson's community about how the FDA works and the role that it play for people with Parkinson's. 158 people from across America viewed the Webcast live. We expect hundreds more people to view the archive of the Webcast on the PAN website here: <a href="http://www.parkinsonsaction.org/news/afternoon-how-fda-impacts-parkinsons-community">http://www.parkinsonsaction.org/news/afternoon-how-fda-impacts-parkinsons-community</a> Because the issue of care giving is critical to the quality of life of the Parkinson's community, the Parkinson's Action Network (PAN) produced and webcasted its "Caregiver Interview Series." Each interview is 12-15 minutes in length, and can be viewed as standalone interviews or together in a series on PAN's website. The interviews took place in June, and the series began being webcast on PAN's website in July. We expect hundreds of people to view these interviews which are linked here: <a href="http://www.parkinsonsaction.org/for-caregivers">http://www.parkinsonsaction.org/for-caregivers</a>					
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## INTRODUCTION:

This grant supported two segments of Parkinson's Action Network (PAN)'s national Webcast Series. The first, held on December 12, 2011, ***How the FDA Impacts the Parkinson's Community***, featured leading experts on this issue. The discussion focused on this 90-minute webcast provided important information to help inform the Parkinson's community about how the FDA works and the role that it plays for people with Parkinson's. 158 people from across America viewed the Webcast live and we expect hundreds more will view the archive of the Webcast on the PAN website here:

<http://www.parkinsonsaction.org/news/afternoon-how-fda-impacts-parkinsons-community>

The second, "Caregiver Interview Series", featured three interviews with experts in the field of caregiving. This series was taped in June 2012, and began being webcast on PAN's website in July. Along with the interviews, PAN also provided a website page of resources for viewers to better educate them on the issues around caregiving. PAN promoted this interview series to the media, as well as to its database of constituents through email, info alerts, and social media. We expect hundreds of people to view these interviews which are linked here: <http://www.parkinsonsaction.org/for-caregivers>

PAN hopes these discussions will prove to be an invaluable resource, not only to the Parkinson's disease community, but all communities focused on these two topics.

## BODY:

### ***How the FDA Impacts the Parkinson's Community***

The Parkinson's Action Network (PAN), like many other disease-focused organizations, is concerned about the lack of therapies that reach the stage of clinical testing and the even smaller number of therapies that ultimately are approved by the Food and Drug Administration (FDA) and made publicly available. Through the generous support of the US Army Medical research and Materiel Command (USAMRMC), PAN hosted a Webcast public panel discussion in Washington, DC on the FDA's role in this process on Monday, December 12, 2011 to educate the Parkinson's community about this issue. 158 individuals viewed this 90 minute Webcast entitled *How the FDA Impacts the Parkinson's Community* live and we expect hundreds more to view the Webcast archive.

This informative webcast provides a unique opportunity to gain valuable insights into the FDA, the role it plays in therapy development, and possible areas for needed change and improvement.

The panel consisted of:

Moderator:

**Amy Comstock Rick, JD**

CEO, Parkinson's Action Network

Panelists:

**Marc Walton, MD, PhD**

Associate Director for Translational Medicine in the Office of Translational Sciences at the Center for Drug Evaluation and Research, FDA

**Michelle McMurry-Heath, MD, PhD**

Associate Director for Science at the Center for Devices and Radiological Health, FDA

**Cartier Esham, PhD**

Senior Director of Emerging Companies Health and Regulatory Affairs for the Biotechnology Industry Organization (BIO)

**Jackie Christensen**

Patient-Representative to the Food and Drug Administration's Office of Special Health Issues

***Caregiver Interview Series***

Because the issue of caregiving is critical to the quality of life of the Parkinson's community, the Parkinson's Action Network (PAN) has produced and has webcasted its "Caregiver Interview Series." Many of PAN's grassroots advocates are caregivers – adult children, spouses, partners, friends – and PAN wanted to provide them with information and resources around caregiving issues and what is available in terms of support from federal, state, and local governments. There are not a lot of policy directives around caregiving because it is a difficult area to measure and quantify. PAN's goal was to educate the Parkinson's community about the needs of caregivers, and also to provide caregivers with information about how they might receive support they need.

PAN CEO Amy Comstock Rick conducted one-on-one interviews with three experts in the field of caregiving:

**Gail Hunt**

President and CEO, National Alliance for Caregiving

**Kathy Greenlee**

Administrator, Administration for Community Living  
and Assistant Secretary for Aging (HHS)

**Angela Robb**

Caregiver, Spouse, PAN Virginia State Director

All three spoke about caregiving as it relates to the Parkinson's community, the aging population, and managing care for a progressive neurological disease for which there is no cure.

**KEY RESEARCH ACCOMPLISHMENTS/REPORTABLE OUTCOMES:**

- Live Webcast held on December 12, 2011 viewed by 158 individuals throughout the country live.
- Archived Emerging Therapies Webcast to be viewed by more than 200 additional individuals over next six months available online at:

<http://www.parkinsonsaction.org/news/afternoon-how-fda-impacts-parkinsons-community>

- Three 12-15 minute one-on-one interviews with experts in the field of caregiving made public in July, 2012.
- PAN promoted this interview series to the media, as well as to its database of constituents through email, info alerts, and social media. We expect hundreds of people to view these interviews which are linked here:  
<http://www.parkinsonsaction.org/for-caregivers>

**CONCLUSION & NEXT STEPS:**

PAN has received very positive feedback from both of these segments of our webcast series. We expect that hundreds more individuals will continue to view them and learn from them over the coming several months. PAN thanks the US Army Medical research and Materiel Command (USAMRMC) for its most generous support of this program.